

"Q&A SESSIONS OFFER PEOPLE FACE TO FACE SUPPORT, TAILORED TO THE ISSUES AFFECTING THEM"

On Wednesday 10 June, to help mark Carers Week, PSPA launched virtual PSP & CBD Q&A sessions using Zoom.

Helpline Team Leader, Julia Brown, said "We've seen a definite increase in the need for Helpline support during the lockdown.

"PSPA wanted to reach out to our members and supporters, to offer face-to-face support about any

issues impacting them each day.

"I hosted the first PSP & CBD Q&A session, called 'Ask the Helpline' using Zoom on 10 June, with my colleague Liz. We had a good number of members and supporters dial into Zoom to ask questions, including; progression of PSP & CBD, how PSP & CBD affects the eyes, speech and swallowing, and how to access respite care in the present climate."



"I WAS INCREDIBLY NERVOUS BUT I DID IT BY DIGGING DEEP AND THINKING OF PSPA"

The postponement of the 2020 Virgin London Marathon was extremely disappointing for all of our TeamPSPA runners.

Understanding the financial impact, the change of date would have on charities like PSPA, the organisers launched the 2.6 Challenge, a UK wide virtual event to help mark 26 April and encourage people to keep fundraising.

Jocelyn Hutchins, tells us how she marked 26 April in Rutland, where she was isolating with her boyfriend.

Jocelyn said: "As I was pepped up for the big day I decided to take on my own marathon in a rural area of Rutland.

"I was incredibly nervous that I wouldn't be able to complete the full distance without the adrenaline and atmosphere of the day. However, I did! In four hours

and 14 minutes!! Digging deep and thinking of the cause, and how close it is to the hearts of me and my family. My mum made cardboard medals and my auntie (who lost her husband to PSP) was thrilled we did it.

"I still plan to take part in October and look forward to seeing everyone there."

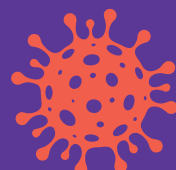
If you'd like to take on your own 2.6 Challenge or lockdown fundraising, please visit: www.pspassociation.org.uk/fundraising/fundraising-during-coronavirus/

Thanks #TeamPSPA for raising **£3738** doing the **2.6 Challenge**



HOW YOU CAN HELP PSPA DURING THE CORONAVIRUS CRISIS

CORONAVIRUS
EMERGENCY
APPEAL



The challenges of living with PSP & CBD don't stop for the Coronavirus. With your help, PSPA's support won't either.

If you'd like to help ensure everyone affected by PSP & CBD continues to receive PSPA's specialist support and information, you can donate to our Coronavirus Emergency Appeal in the following ways, to give what you can:

TELEPHONE
01327 322414

ONLINE
www.pspassociation.org.uk/emergencyappeal/

POST
Please send a cheque made payable to PSPA to FREEPOST PSPA

JUNE 2020 UPDATES

WELCOME

We all know the challenges of living with PSP & CBD can turn lives upside down. And that's without the unprecedented changes the world has seen recently.



Many of us are now staying at home as much as possible, relying on technology to connect us with colleagues, friends and most importantly family. We understand how difficult this can be, particularly for the PSP & CBD community, whose care needs demand extra time, effort and attention.

Protecting our loved ones at this difficult time was a top priority for PSPA, and as such we quickly adapted our services, ensuring even the most vulnerable continue to receive specialist support and information.

Our Helpline has remained open throughout the lockdown and with the support of our fantastic volunteers, companionship offered over the phone to anyone feeling isolated at this time.

We've joined forces with other charities to ensure our community's voice is heard across matters including research, access to food, medical support and benefits.

As you will read later, PSPA Local Groups have been trialling different methods of staying in touch.

We've also produced this newsletter, so you can keep up to date with what is going on.

Although shops are beginning to open up and some Primary School pupils have returned to class, as the new 'normal' begins

to establish itself, unfortunately, the impact of the Coronavirus crisis will be felt by us as a community, and as a charity, for many more months to come.

Stay safe and thank you for your continued support.

Andrew

Andrew Symons,
Chief Executive

DATES FOR YOUR DIARY

20 to 27 July PSP & CBD Awareness Week

23 July Online Summer Raffle launches

24 July PSPA Tea-Parties launch

September Christmas cards and humming birds available

21 October PSPA Matters

October Bauble Appeal launches

PSPA

SUPPORTING YOU AT THIS DIFFICULT TIME

Despite the UK lockdown, PSPA's support continues.

If you need support urgently or just want to chat through your symptoms, our Helpline is still available, Monday to Friday, 9am to 5pm. And 7pm to 9pm on Mondays, Wednesdays and Fridays.

To get support, please call us on **0300 0110 122** or email helpline@pspassociation.org.uk

If you would like to register to receive regular phone calls from one of our volunteers, please email us at volunteering@pspassociation.org.uk

"We're such a close-knit group, having the opportunity to see each other virtually, was great."

We've been talking to PSPA Local Group Coordinators to find out how they have been keeping in touch with members during the UK lockdown.

ZOOM CATCH-UPS

The Isle of Wight Local Group were the first to trial Zoom meetings.

Coordinator Becky Gell said: "We're such a close-knit group, like a family, and so not seeing each other was hard so when Zoom calls were suggested by PSPA to us, we jumped at it. The opportunity to see each other virtually, was great. Carol from PSPA scheduled the meeting and sent the invites out, so we just needed to run the meeting on the day."

BE IN WITH A CHANCE OF WINNING £500 THIS SUMMER

Our popular **summer raffle** is launching online on 23 July.

You can play your part in improving the lives of people living with PSP & CBD by buying your tickets online at our website: www.pspassociation.org.uk/summer-raffle/

Tickets cost £1 each and you could win £500!

If you have only just set up an email account, update your contact details by emailing info@pspassociation.org.uk to keep up to date with all the raffle news.

Vikki Colenutt continued: "Having never used Zoom before, I found the whole process very easy. It was lovely to see everyone and check that they are all getting on ok in the current situation."

Brian and Carol dialled into the virtual meeting, they said: "We have all become good friends, so whilst we cannot meet up and have a hug, at least we can see each other safely until things get back to normal."

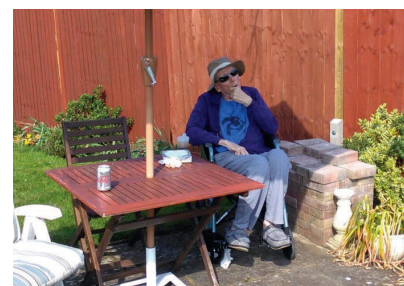
REGIONAL ZOOM CATCH UPS

A number of regional catch ups will take place via Zoom over the coming months, these include:

Thursday 25 June at 2pm
South West Peninsula

Thursday 9 July at 2pm
South Wales

Thursday 22 July at 2pm
South of England



RING AROUND AND NEWSLETTERS

Hertfordshire Local Group Coordinator Maureen Horne, has been working tirelessly to stay in touch with the group members too.

Maureen said: "Many of our members do not use the internet, so when the lockdown was declared I wanted to find ways of staying in touch with as many members of the group as possible. I have been telephoning members who usually attend meetings for catch-up chats, offering me an opportunity to learn more about the group members as well as exchange tips about such matters as how best to access supermarket home delivery slots!

"For those on email, and this includes a wider group of around 65 people, we regularly exchange amusing videos and quizzes. I also send out my newsletters to the group, either by email or post."



WHATSAPP GROUPS

The Leicester Local Group has been staying in touch with each other by creating a WhatsApp group and have scheduled in coffee and chat sessions to ensure members can have a good catch up.

Coordinator Harinder Kang said: "We set up a WhatsApp group at the end of March to help members of the Local Group stay in touch whilst meetings are unable to take place. Of our 11 group members, nine are active in the WhatsApp group. As well as updates and photos, we've scheduled in four chats across the past couple of months. We talk about everything from how everyone is feeling, to celebrating the lovely weather, Easter and birthdays. Everyone seems to be well, keeping busy and staying positive during this time."

For more information about PSPA Local Groups, please visit: www.pspassociation.org.uk/information-and-support/living-with-psp-cbd/your-local-group/



"I SHAVED MY HAIR OFF IN TRIBUTE TO MY HUSBAND AND TO FUNDRAISE FOR PSPA"

Carol Bartrop raised almost £700 for PSPA this spring when she shaved off her hair to fundraise in memory of her husband, Paul, who passed away from PSP in September 2019.

Carol said "I wanted to do something in tribute to Paul to help mark his birthday on 29 March as well as fundraise for PSPA.

"I decided to shave off my hair as I thought it would help to raise awareness of PSP and the enormous impact it has on peoples' lives. As well, it was a great fundraiser for PSPA, to help them get to the root of this little-known degenerative disease.

"I was overwhelmed by the generosity of my family and friends who sponsored me. It was great to read all the messages of support and to see how much Paul is loved and missed."

To read more about Carol's hair shave and to sponsor her, please visit:

www.justgiving.com/fundraising/carol-bartrop

